

Pennsylvania Message

IMAGINE DIFFERENT...ACHIEVE DIFFERENT! FAMILY LIFE FOR ALL CHILDREN WITH DISABILITIES IN PENNSYLVANIA



**Imagine different:
Achieve different!**

Did you know?

Hundreds of children with developmental disabilities in Pennsylvania are not growing up with families. Instead, they are living in facilities. Hundreds more are at risk of admission to facilities. Why? Because it is often easier to place a child in a facility than to get the supports and services needed for the child to grow up in a family home.

Working for change

The **Imagine Different Coalition** represents the grassroots effort of a passionate and informed group of parents, individuals with developmental disabilities, advocates, and professionals from across Pennsylvania. We have come together because of a common concern—the number of children with disabilities who are growing up in congregate care facilities.

The Coalition emerged in May 2014 from a grant with the Pennsylvania Developmental Disabilities Council to the PEAL Center. A grant from the Edith L. Trees Charitable Trust now enables its continued work.

Beliefs drive change efforts

The Coalition believes that every child should have the opportunity to grow up in a loving family. We believe facilities cannot meet the most important need of childhood—the daily experience of love and a sense of belonging that are uniquely offered by families. Coalition members have both deep personal experiences with children with disabilities and knowledge about how the system works in Pennsylvania. We have also learned how other states have successfully redirected resources to support families and reduced the need for facilities. The Coalition's goal is to educate others throughout Pennsylvania about what is possible. We want the Commonwealth's resources and activities to support family life now and into the future.

In this issue of the [Pennsylvania Message](#), information is shared by the Imagine Different Coalition. Find out about their important work and how you can support it.

IMAGINE DIFFERENT . . . ACHIEVE DIFFERENT COALITION MISSION

. . . to champion systemic change and the development of community support to ensure that every PA child with disabilities who lives in or is at risk of being placed in a congregate care setting can alternatively grow up in a well-supported and loving family.

President's Message - Mike Marsh



HOT TIMES IN THE SUMMER...

It is my hope that each of you have had a good summer whether you are spending time with family and friends, catching up at home, or just taking a few minutes to enjoy the warm sun between meetings and events. In June, I had the great honor of being elected president of The Arc of Pennsylvania. I feel a bit inadequate when I look at those who have preceded me in the role. I pause to say thank you to Ken, Jeannie, and Paul who served with great care and solid leadership during times of challenge and triumph.

Along with the executive committee I will endeavor to pick up where they left off and help us advance.

As a volunteer, I am struck by the awesome dedication we have among our members, executives, and boards across the Commonwealth. The thousands of hours spent locally and at the state chapter level have an impact on the people of this Commonwealth that is without measure. When I think about the advocacy so many of you do every day, I am deeply grateful. When I think of the difference being made through programs like Discovery and Include Me From the Start for not only people with intellectual and developmental disabilities but for everyone around them I am grateful.

I am proud of the work of The Arc of Pennsylvania. What is achieved by this state chapter is valuable and inspiring, especially when you look at the small professional staff we have. However, The Arc has always been a grassroots organization of parents, friends, self-advocates, and well... people. The local chapters are the power base that enables the state chapter to accomplish so much. It is at the local level that the daily needs of people are met, challenges are overcome, advocacy has its most direct impact, and lives are changed. It is my sincere hope that we will find a way to grow and build an even stronger organization by challenging each other, supporting each other, and taking care of each other.

Over the last two months there have been great victories such as the approved spending bill for the Commonwealth and a great Advocacy and Policy Day. Then we saw great challenges like the Welfare Code and lack of a balanced spending plan for Pennsylvania. When I wrote to my legislators it was my intent to bring to the front of their consciousness their responsibility to care for those who need supports to live their full potential. The heart of The Arc is advocacy and the feet of The Arc will continue to be the programs and outreach so desperately needed every day. The references to The Arc heard in the legislative chambers and in hearings during the budget process reinforces the impact we can have when we take a couple of minutes to reach out and use our voices.

Over the next year, let's focus on how we find the talents and passions of our boards and our members and focus them in ways that allow us to be a force multiplier. It will take everyone giving their best and sharing ideas. I challenge each of us to find new ways to invest our time, talents, ideas, and financial support in our common purpose: promoting the human rights of people with intellectual and developmental disabilities and supporting their full inclusion and participation in the community.

Finally, I leave you with a quote - not the one that I originally picked, but one that I find powerful:

“Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it's the only thing that ever has.”
-Margaret Mead



The Arc.

Pennsylvania

Suite 403 – Pennsylvania Place
301 Chestnut Street
Harrisburg, PA 17101
717-234-2621
www.thearcpa.org
The Arc of Pennsylvania

Board of Directors

Michael Marsh, Montgomery
President
Sarah Holland, Lancaster
1st Vice President
John Goryl, Dauphin
2nd Vice President
Joshua Stranix, Schuylkill
Secretary
Jessica Capitani, Dauphin
Treasurer
Ken Oakes, Philadelphia
Immediate Past President
Maureen Westcott,
Lancaster PCE Representative

At Large Members

M.J. Bartelmay, Mercer
Frank Bartoli, Luzerne
Lisa Butler, Cumberland
Richard Chamovitz, Delaware
Cindy Dias, Greene
Hallam Harper, Montgomery
Gary Horne, Allegheny
Gerald Krall, Dauphin
Pat Leo, Philadelphia
Lisa Long, York
Michael Owens, Delaware
Lucille Piggott-Prawl, Monroe
Laura Princiotta, Philadelphia
Phil Rosenbauer, Butler
Christopher Schwenk, Delaware
Sara Wolff, Lackawanna

The Arc Staff

Maureen Cronin, Executive Director
Anne Yanikov, Director, Advocacy and Governmental Affairs
Diane Keefer, Financial Director
Alexa Brill, Social Media & Website Manager
Amy Houser, Administrative Support
Matthew Stinner, Self-Advocacy Engagement Consultant
Rita Cheskiewicz, Program Director, Include Me Initiative
Claire Sonneborn, Assistant Program Director, Include Me Initiative
Mary Mahoney-Ferster, Program Specialist, Early Childhood, Include Me Initiative
Nicole Turman, Program Manager, ADEPT
Anthony Chan, Assistant Program Manager, ADEPT
Gwen Adams, Operations Director
Shirley Keith Knox, Editor, PA Message

Executive Director's Message

Maureen Cronin

Together Change Happens

The PA Message is a great opportunity for The Arc of Pennsylvania to share how lives are being changed. This happens because we do it together. Change is most likely to occur when passionate people focus their sights on a shared outcome - to ensure that children and adults with intellectual and developmental disabilities receive the supports and services they need, are included in their community, and have control over their own lives. Our accomplishments over these past few months have been successful only because we have been a formidable force at the federal, state, local, and individual level.



The Commonwealth of Pennsylvania just passed a budget that offers the highest level of support to people with disabilities that we have seen in recent years. The \$26.2 million in the Department of Human Services budget ensures that 820 high school graduates will receive supports so they can transition to community living and employment. Additionally, it provides funds to serve 1,000 people currently waiting for emergency services through a new Community Living waiver option. Increases in state funding for special education and early intervention services are also included in this budget recognizing the importance of the youngest of our citizens and their families.

While the budget was passed, the spending plan was not and as of this writing, we are still awaiting final decisions for a balanced spending plan. The impact of The Arc movement was felt when we flooded the PA Legislature with messages stating our opposition to any changes in the Welfare Code. These changes would have drastically impacted the Medical Assistance (MA) "loophole" imposing a premium on MA benefits. We believe that the budget should not be balanced by increasing a parent's cost of raising a child with significant disabilities.


Another call to action - the congressional consideration of the Health Care Freedom Act (S.A. 667 to H.R. 1628). In Pennsylvania, the intellectual disability and autism community system almost completely depends on state and federal Medicaid funding. This funding covers the cost of critical services and supports that keep individuals living in their homes and in their communities. Medicaid pays for services for people seeking employment and other community opportunities. The result would have reduced access to health care and cut much needed home and community services. Our network responded with letters, emails, calls, visits to members of the PA delegation, town halls, and rallies. The defeat of this disastrous health care bill is a huge win for people with intellectual and developmental disabilities and their families.

This issue highlights a little-known fact - there are children growing up in congregate facilities. These children are growing up without a nurturing family, often because families cannot access the supports and services they need to keep their child at home. I am glad we have this opportunity to share this information with our membership. Check out the Imagine Different resources and connect with them.

There is still much work to do and staying connected is absolutely necessary.

A handwritten signature in black ink that reads "Maureen Cronin". The signature is fluid and cursive, written over a light blue horizontal line.

***“To whom much is given, much is required –
not expected, but required.”***
– Andrew Young

 Find Us on Facebook

 & Connect with Us on Twitter

Achieve with us.

THE DEVELOPMENTAL IMPERATIVE

Developmental benefits of family life

Children have a developmental need for family life. Both research and child development experts offer clear evidence of the developmental benefits of family life. The primary feature of family life is an enduring, nurturing parental relationship. The parent-child bond -- the feature at the heart of family life -- is responsible for feelings of safety, security, and a sense of love and belonging that are critical to a child's optimal growth and development.

Developmental risks of institutionalization

Robust evidence has identified conditions that impede good outcomes for children. Even the best congregate care settings are missing the factors embedded in most families that are essential for healthy development. Characteristics of facilities that are potentially harmful to children's development include:

- (1) a large ratio of children to caregivers
- (2) absence of a primary caregiver for each child
- (3) turnover of caregivers
- (4) insufficient cognitive, language, and socioemotional stimulation
- (5) regimented schedules and lack of spontaneity in child-adult interactions
- (6) limited peer-to-peer interactions. *

Assuring developmental opportunities

Many families of children with disabilities face challenges to providing the home they want for their child. Our collective effort is needed to figure out how to support families and make facilities unnecessary.

Footnote: *Friedman SL, Norwood KW, AAP COUNCIL ON CHILDREN WITH DISABILITIES. *Out-of-Home Placement for Children and Adolescents with Disabilities—Addendum: Care Options for Children and Adolescents with Disabilities and Medical Complexity. Pediatrics.* 2016;138(6):e20163216.

However loving and kind:

- Facility staff cannot replace the parent-child relationship
- Families cannot fulfill their role without support



AACCOMMUNITY.NET IS LIVE!

Do you know someone who communicates without speaking? Whether it is by the use of facial expressions, gestures, or texting - there are moments when each of us communicate without talking. For some of us, non-speech communication is necessary all the time.

Folks who communicate without speech might require Augmentative or Alternative Communication (AAC) systems. AAC is any form of communication other than spoken language used to express thoughts, needs, wants, and ideas. AAC can range from body based (i.e. gestures) to high tech tools with touch screens or eye gaze.

AACCommunity.net is a new web resource for all things related to AAC. It provides resources for all involved in AAC - users, families, speech therapists, makers, sellers, and others. We have lots of ideas, tips, and advice at this website.

Today, 67% of Pennsylvanians with complex needs do not have access to a robust communication system. Communication connects us to each other. Communication is at the heart of everyday activities. We need to communicate to find and keep a job, live independently, make friends, etc. Communication creates community. Communication is a human right.

AAC Community unites all people concerned with communication rights for Pennsylvanians with disabilities. Intellectual disability, autism, and movement difficulties can create complex communication needs. AACCommunity.net is a place for AAC users to connect with each other. It is also for those of us involved in supporting people with complex communication needs. It includes a directory of vendors, fabricators, specialists, thought leaders, research, and advocacy groups. We also link to articles and blog posts by members of the broader AAC community nationally.

Are you trying to figure out how to fund an AAC device? Check out the page on funding resources. Do you have something to share about AAC? Perhaps an event, research citation, strategy, or tip? Please submit content to the site and join in the conversation!

This resource is possible with funding from the Pennsylvania Office of Developmental Programs to the Institute on Disabilities. Pennsylvania's Initiative on Assistive Technology developed and supports this project. This Assistive Technology Initiative is one of the programs of the Institute on Disabilities at Temple University. A related program is our statewide Assistive Technology Lending Library. In addition to other forms of assistive technology, the library contains many speech-generating devices and apps. We ship these devices directly to your home for a trial period, free of charge. You can find a link to the lending library at www.AACCommunity.net.

If you or your loved one talks without speech, check out www.AACCommunity.net. Sign-up for the newsletter and share it with your team. For additional information, contact our team at:

Kim Singleton, Director of Assistive Technology Programs, Institute on Disabilities, Temple University: kim.singleton@temple.edu

Kathryn Helland, AAC Specialist, Institute on Disabilities, Temple University: kathryn.helland@temple.edu

PENNSYLVANIA CHILDREN IN CONGREGATE CARE FACILITIES: FAQs

What is the problem?

Hundreds of children with disabilities are growing up in congregate care facilities even though family-based alternatives are more desirable and feasible.

Why are children placed in facilities?

Many factors contribute to the placement of children in facilities. Common factors include:

- Lack of adequate support for a child with complex medical or behavioral needs
- Lack of family support such as respite, home modifications, and in-home assistance
- Unavailability of services covered by the Medical Assistance program
- Long waiting lists for services
- Limited awareness or knowledge of available Medical Assistance services
- Family situations intensified when caring for children with complex needs
 - Parent illness or disability
 - Inadequate housing and/or transportation
 - Competing responsibilities for other children or extended family members
 - Inability to afford costs related to the child's needs
 - Inability to find or afford child care preventing or limiting parent employment
- Lack of voluntary options for placement with another family, including Lifesharing

Factors in the child welfare system that contribute to placement of children in facilities include:

- Lack of family services, including foster homes
- Low reimbursement rates for specialized foster homes
- Inadequate services, supports, and respite care for foster families
- Faulty assumptions that available foster families are unwilling or unable to care for children with disabilities

Factors that cross systems include:

- Resources disproportionately directed to facilities instead of family support
- Limited access to Medicaid waivers that support family-based alternatives to facilities
- Lack of interagency collaboration

Who pays for children's placement in congregate care facilities?

The vast majority of placements are funded by the Medical Assistance program (either directly or through managed care organizations) and/or the child welfare system. Additional payers may include private insurance, private pay, or funds from counties, the juvenile justice system, and school districts.

How can we solve the problem?

The factors that contribute to placement of children in facilities are complex and will require multiple strategies to solve. The following changes would contribute significantly to reducing the number of children growing up in facilities. Each of

these elements has been demonstrated to work in other states and some have been demonstrated in a limited way in Pennsylvania.

Changes in Policy

- Prioritizing family life over congregate care facilities for children
- Prioritizing resources for family support
- Developing a comprehensive plan for children that crosses state agencies

Increased Resources

- Increased funding and flexibility of services for family support and foster care
- Increased access to Medicaid waivers providing community support as an alternative to facility placement for children of all ages and all developmental disabilities
- Waiver amendments to expand services, including Lifesharing

Enhanced Processes

- Permanency planning for all children currently living in facilities or at risk of admission
- Increased awareness of how to access all services covered under EPSDT (Early and Periodic Screening, Diagnosis, and Treatment)
- Facilitators to help families explore alternatives and connect to the resources necessary to enable their children to live in family homes
- Tracking of all children with disabilities living long-term in congregate care facilities
- Access to waiting lists by children living in facilities
- Recruitment and development of Lifesharing families

DEFINITIONS:

“Congregate care” means a facility that houses multiple individuals. It can take many forms including nursing facilities, Intermediate Care Facilities, residential treatment facilities, and psychiatric institutions. Some facilities are designed for long-term care. Others intended for a short-term stay become extended to a long-term residence.

“Family” or “family-based alternative” means living with parents, other relatives, or other families. Families can take many forms (nuclear, extended, multi-generational, parenting across multiple households, foster families, adoptive families, and Lifesharing). Common to all healthy and safe families is the presence of at least one loving adult committed over the long term to nurture, guide, and assure a secure home throughout a child's life.

“Lifesharing” is a living arrangement where parents voluntarily choose another family to share care of their child while they continue to be closely involved and maintain their parental rights and decision-making.

“Permanency” is a policy framework and a set of practices based on the principle that stable family life and enduring parental relationships are essential to a child's development and well-being.

UNPACKING THE PROBLEM

Nancy Rosenau, Ph.D.

The Imagine Different Coalition works to assure a family life for all children with disabilities. Sometimes people ask us if we really mean *all* children. The skeptical thought (spoken or not) is “*Don’t some children need facilities?*” The fact is some children do have significant care issues. These issues can be challenging and may require specialized expertise and interventions. But can a facility meet the needs of these children better than a family? Let’s unpack that view of the problem.

Whether a facility is an Intermediate Care Facility (ICF), nursing home, or other long-term congregate care residence, these “special” places for “special” children are really about two elements: (1) a physical environment, and (2) a peopled environment.

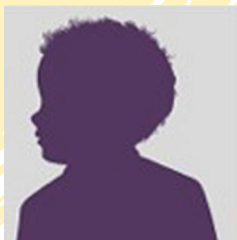
1. The physical environment. Any residential setting is a set of rooms in a building with particular features. Some rooms house equipment (e.g., cooking, therapy, or medical); some separate children from each other (e.g., for behavioral or infection control); some group children together (e.g., dining rooms or activity rooms). But if we look at any single child, it is hard to conclude that *This Child* needs a building shared with 25 or 100 other children with equally complex needs. On close examination, the physical space does not offer something that cannot be replicated or improved on in another building with fewer rooms and fewer roommates—a family home.
2. The peopled environment. Any residential facility is also a set of people. A critical issue for children with complex

needs is often access to people with particular expertise and available time. The people most often referenced for children with complex needs are nurses, psychologists, or behavior specialists. However, if we examine how many hours a day these professionals actually spend with a particular child, we find most care is provided by an aide with a more modest amount of training. On close examination, the peopled environment does not offer something that cannot be replicated or improved on in another building by changing people’s job site—to a family home.

We need to shift our thinking to see that the problem doesn’t lie in the child. The problem lies in the arrangement of our services. The question, “*Do some children need facilities?*” can be reframed as: “*How can we organize our assistance to provide it in a family’s home? Can we reduce the need for facilities by organizing our assistance differently?*”

Without a doubt, getting enough people with time and expertise into family homes is a managerial challenge. To be sure, supporting children in family homes requires policy and funding changes. It also requires systematically tackling each and every child and family on their own terms to figure out family-based arrangements that work.

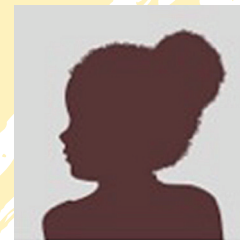
For many years I have worked to help children growing up in facilities to find their way to family homes. Along the way we met children like Marco, JaMal, and Tiffany—kids with the kind of needs that initially seemed too difficult to a lot of us.



Marco had been in a coma due to injuries from a car accident. He needed specialized medical equipment and supplies for nourishment, breathing, and repositioning. His family had to overcome not just their lack of knowledge about his care, but also their fear. Motivated by love, they became skilled in providing his care in the facility under the nurses’ watchful eyes. What kept Marco in a facility was not his coma or his family’s skills, but the fact that his family home was not accessible. By arranging different housing and relocating nurses, Marco’s family was able to take him home.



JaMal was placed in a large facility when his family felt they couldn’t protect his younger siblings from unintended consequences of his behavior. Later JaMal’s family was introduced to the idea of a Lifesharing family. His mother’s initial response was, “It’ll never work.” But she was willing to consider it so JaMal could live closer. To her own surprise, JaMal’s mother was attracted to one proposed family who she subsequently chose for her son. The two families have since built a shared parenting relationship. JaMal’s mother says of the mother in the Lifesharing home, “She’s like a sister.” This newly extended family socializes together with JaMal spending time with his two loving families.



Tiffany needs a gastrostomy tube for nourishment and a ventilator to breathe. Her caregivers need to know how to judge her breathing, adjust her vent settings, and suction her airway. Her family was frightened of the equipment and the difficulty of caring for her at home. Tiffany’s parents were helped to make a loving decision that enabled their daughter to enjoy family life. Tiffany went to live with an aide from the nursing facility who also loved Tiffany and was comfortable with her care.

[continued on page 7](#)

Neither Marco or JaMal or Tiffany needed a facility. What they needed was to live with people who loved them and had enough support. I am not saying that solutions are readily available. But asking “What will it take?” raises more surmountable problems than asking “Don’t children like this need a facility?”

The good news is that unpacking the problem can break down imagined difficulties. This is as true for planners as it is for families. Our worries about children whose needs we fear are too complex arise from letting our imaginations go unchallenged.

The bad news is that too often families have not had people to help, or the promised help didn’t show up, or wasn’t as expert as their titles suggested. Unfortunately, this is no less true in facilities that struggle with recruiting staff, no-shows, turnover, and too few staff across too many residents.

Seeing the child as the problem prevents the real work. If we unpack the care in most facilities and see it as essentially people in buildings, we can see how arrangements can be rearranged. Then alternatives become imaginable and ultimately doable, given enough ingenuity and a committed group of problem-solvers. We can dissect the actual facts to do the real work of supporting children in family homes.

Footnote: This article was adapted from the original “But aren’t there some people . . . ? Dispelling the Myth,” published in *TASH Connections*, Volume 30, Issue 3/4, March/April 2004.

Dr. Rosenau is a national expert on family-based alternatives to congregate care and retired Executive Director of EveryChild, Inc. Texas, an organization whose mission is to create a system that ensures children with disabilities grow up in families instead of institutions.



FAMILY LIFE FACILITATORS: ONE OF THE ANSWERS TO THE PROBLEM

The Imagine Different Coalition is working to promote the role of a “Family Life Facilitator.” This role has been used by other states to dramatically reduce the use of facilities by children.

What is the role of a facilitator?

The facilitator’s role is to focus on children with developmental disabilities growing up in facilities. Facilitators have the time, energy, know-how, and persistence to figure out how to do whatever it takes to help a child return to family life. The facilitator’s role precedes and/or supplements work with a supports coordinator or supports broker. Facilitators reach out to families to help them imagine family life before they can effectively use the help offered by a supports coordinator or supports broker to achieve it.

The importance of outreach to families

Helping families to consider an alternative to a facility for their child requires assertive outreach. Families may not initiate or welcome consideration of an alternative to a facility—they may be too leery or weary to consider a change after the emotionally-charged decision to place their child. They may feel “finally settled” after a difficult time. Considering a change requires much more than information about services. It requires intentional, thoughtful, and guided exploration of new or different ideas, sometimes challenging previous perspectives, and sometimes improving on previous supports.

Some families are comfortable with their child living in a facility. Others would prefer a change. In both situations, the work of the facilitator begins by understanding what has shaped a family’s views and decisions. The facilitator’s relationship is the primary vehicle to building the trust needed to explore pathways to family life.

Considering a return home

Considering a return home is essentially about envisioning what kind of support would make home life feasible. The work begins with imagining a successful return home—not with a list of services, programs, providers, or funding. A facilitator first needs to hear a family’s dreams and fears in their own terms.



Randy needs a ventilator to breathe, a gastrostomy tube for nourishment, and an adapted wheelchair for mobility. He was placed at

birth in a pediatric nursing facility. A facilitator reached out to Randy’s mother to consider other options. Randy’s single mother described feeling alone, her spotty work history, frequent moves, and broken-down car. She knew about in-home nursing, medical equipment, and supplies, SSI (Supplemental Security Income) and Medicaid. But for her son to return home, she had to first see how to find and afford an accessible house and vehicle. A full picture preceded linking her to services and supports that enabled Randy to return home.

Sara’s mother to the facilitator working with her: “I talked with a service coordinator before who told me about waivers, but I didn’t understand that a waiver meant I could choose a family. She gave me this list of providers and its 20 pages thick! I mean, how are you supposed to know? With you, I could actually understand everything. You were with me every step to find a family that would be good for my child. You will always be treasured by our family.”

Considering another family home

While the parents' dearest desire may be having their child at home, they may not feel it is possible even with additional supports. Sometimes extended family members can be supported to care for a child. But if neither is possible, the facilitator's role is to help a family see how another family could care for their child. The idea of someone else caring for their child may not seem appealing or might be rejected out-of-hand. It is critical that the facilitator introduce family living arrangements where parents voluntarily choose another family and retain their rights and decision-making and continue to be closely involved. "Lifesharing" can be such an arrangement. A Lifesharing family can become like extended family. When a child cannot return home, a Lifesharing family can provide practical assistance to parents while enabling their child to enjoy the benefits of family life. Parents who have chosen Lifesharing have found that having another family who loves and values their child has been supportive to them as well as their child.



Aaron uses a wheelchair and needs help with all his daily needs. His mother cared for him alone after her husband's death. Then she developed a degenerative health condition. She turned to the system for help. She accepted the only option offered—a large facility located two hours away. A facilitator learned about Aaron and met with his mother to talk about alternatives. The facilitator described a Lifesharing family. Aaron's mother's reaction was, "Nobody told me there were families who would do this. If he can't live with me, I would rather have him with a family."

Working with a provider organization, a Lifesharing family was found near her who had experience with children with developmental disabilities. They understand Aaron's mother's situation and take her to spend time with her son. Families whose children have moved from facilities to family life report that a facilitator was key to helping them imagine the possibility and then achieve it.

Considering children in child protective custody

When a child's parental rights have been restricted, a facilitator can be beneficial in working with a child's Children and Youth caseworker. Children with disabilities or complex medical needs in the child welfare system too often grow up in facilities rather than families. Unfortunately, misconceptions about disabilities and disability services are prevalent. Caseworkers and foster care providers may view children with



disabilities as ill-suited for family-based placements or mistakenly assume foster parents would be unable or unwilling to care for them. A facilitator can provide much needed assistance in correcting misperceptions and challenging faulty assumptions.



Marcus has cerebral palsy and a mild intellectual disability. After entering the child welfare system at age 12, Marcus spent most of his

adolescence in a residential facility. His caseworker felt the facility provided specialized services. She didn't pursue foster care. A facilitator learned about a staff member at the facility who Marcus was close to. She learned he was interested in opening his home to Marcus. She helped him to become a foster family. Marcus went to live with the staff person who now considers him a part of his family.

There are many pathways from facilities to family life. The facilitator's task is finding one that works.

GO GREEN

The Pennsylvania Message is now available via email. Please send your full name, local chapter, and email address to: ahouser@thearcpcpa.org to receive your electronic copy.



LEARN MORE / DO MORE

Stay Informed with PIE - The Policy Information Exchange (PIE) covers policy issues for Pennsylvanians with disabilities, their families, and advocates. The Arc Pennsylvania manages PIE for the PA Developmental Disabilities Council.

Email us at pie@thearcpcpa.org to receive electronic alerts and the quarterly newsletter.

PARTNERING TO ACHIEVE FAMILY LIFE

Reducing the need for children with disabilities to live in facilities requires partnerships among advocates, state agencies, and providers. The good news is that such partnerships are emerging.

The Department of Human Services (DHS) has increased its attention to children with disabilities living in facilities and invited the Imagine Different Coalition to participate in bi-monthly meetings since December 2016. The meetings include other state departments including:

OMAP (Office of Medical Assistance Programs)

ODP (Office of Developmental Programs)

OCYF (Office of Children, Youth and Families)

OMHSAS (Office of Mental Health and Substance Abuse Services)

- Each DHS office discusses high-level strategies to support the transition of children to family life.
- ODP has hired a Transition Coordinator whose sole role is to work on systemic issues facing children living in facilities and find ways to transition to family life.
- ODP has received approval for Medicaid Waiver amendments to increase services for children.

“Supporting a child, no matter the level of disability, in a typical home setting is always preferable. Couple that with open-ended support for the child’s natural family, or alternate family when necessary, and we’re talking about a life-changing approach to care, not only for the child but for the child’s parents, siblings, friends, and neighbors.”
Stephen H. Surovic, COO & Director, Intellectual/Developmental Disabilities Division Rehabilitation & Community Providers Association

The Rehabilitation & Community Providers Association (RCPA), an organization that represents member provider organizations, has formed a Children in Congregate Care working group. They have invited representatives of state agencies and the Imagine Different Coalition to come together to work on ways to achieve family alternatives to congregate care facilities.

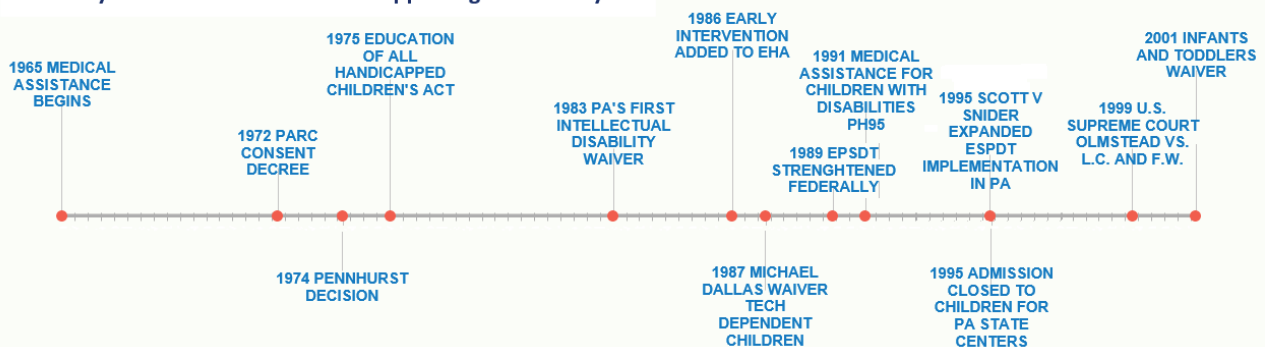
The Lifesharing Coalition represents agencies and families providing Lifesharing. The Coalition has invited the Imagine Different Coalition and state offices to present at their conferences and participate in their ongoing meetings.

“The State Lifesharing Coalition is excited about exploring the possibilities and working collaboratively toward serving children in Lifesharing.” Kathy Trumbore, Lifesharing Coalition Leadership.

“The mission of the Office of Developmental Programs is to make it possible for every person to live an Everyday Life. For children, an Everyday Life begins in infancy in the arms of loving parents whose constant love and attention provide the security, sense of belonging, and the stimulation essential to a child’s optimal growth and development. As children grow, an Everyday Life means living within a family where relationships continue to be the foundation for learning and healthy development. To assure children this Everyday Life, we have to support families, helping them develop a vision for their children and giving them the tools and support to achieve that vision. For some children, that loving family may be an alternate family who willingly welcomes a child into their home.”
Nancy Thaler, Deputy Secretary, PA Department of Human Services, Office of Developmental Programs



Advocacy Laid the Groundwork for Supporting Community Life



ADEPT: ARC DISCOVERY EMPLOYMENT TRANSITIONS

ADEPT is The Arc of Pennsylvania's customized employment program. The Arc PA supports individual's with significant impact of disability to seek and maintain employment in their community. The Arc PA's consultants are trained and nationally certified by Marc Gold & Associates, a national leader in customized employment. Individuals and agency's interested in seeking certification in Discovery, Job Development, or Systematic Instruction can contact The Arc PA for additional information.

What is Discovery?

Discovery is an alternative vocational assessment that seeks to answer the question, "Who is this person?" Our consultants answer this question by getting to know the individual through interaction, observation, and interview in order to develop a comprehensive profile. Discovery is a non-traditional, no-fail process which informs and directs the employment process. Our nationally certified consultants identify the strengths, interests, and conditions for success of the individual.

Discovery is the foundation to develop customized employment. After completing a Discovery Profile for the job seeker, a consultant facilitates and develops a Customized Plan for Employment. This plan for employment directs customized employment job development activities. A visual resume is also developed for each job seeker.

Discovery takes approximately 12 weeks to complete. The certified consultant will spend about 6 weeks with the job seeker, examining all aspects of his or her life at home and in the community. An additional 6 weeks are used to develop the profile, customized plan for employment, and the job seeker's visual resume.

Customized Employment/Job Development

Customized Employment Job Development is unique because of the focus on the employer. Consultants conduct a benefit/needs analysis with a business as they consider how the job seeker's interests, contributions, and conditions for success can improve the business. Job development occurs as the consultant negotiates a customized job description for the job seeker. This provides mutual benefit to both employer and employee.

Systematic Instruction

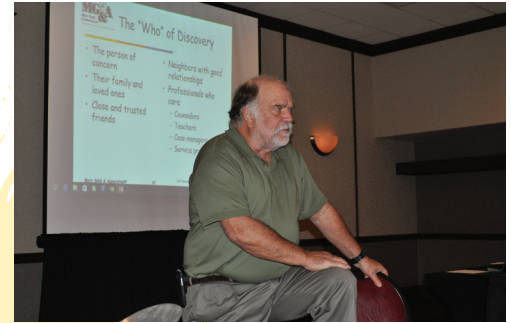
Systematic Instruction is the process used to teach the ADEPT participant the tasks of the job secured through the customized employment process. Systematic instruction employs the methods of Marc Gold's *Try Another Way* approach to teaching job skills.

What is customized employment?

Customized employment is a job that meets the needs of both the employer and the employee. The customized employment process is designed to match the identified contributions of a job seeker with an employer. A successful match improves the business's bottom line by addressing unmet needs, improving productivity, and/or improving efficiency.

For additional information, contact Anthony Chan at achan@includemepa.org .

DISCOVERY AND CUSTOMIZED EMPLOYMENT TRAINING AVAILABLE



The Arc Pennsylvania recently hosted Mike Callahan and Teresa Callahan from Marc Gold & Associates. They presented training for Discovery and Customized Employment, effective strategies for getting individuals with significant disabilities a job. This training was held in Cranberry Township, Butler County. There was record turn out! The focus of the three (3) day training is learning to see the best in individuals and create customized jobs in the community that align with the job seeker's strengths, interests, and conditions for success. Attendees of the 3-day training qualify to complete an intensive 20-week certification program which will meet qualification requirements to provide Discovery and Customized Employment/Advanced Supported Employment services funded through the Office of Developmental Programs (ODP) and the Office of Vocational Rehabilitation (OVR). To learn more about Discovery and Customized Employment, contact The Arc PA.



HELPING CHILDREN MOVE TO A FAMILY HOME - KEY LESSONS LEARNED

In the course of thirty years' experience in other states, working with hundreds of families to help children move from congregate care facilities to family homes, we learned three key lessons.

Lesson 1: Systems need to reach out to families of children living in facilities. It was only through active and respectful engagement that movement to a family became the preferred choice of families. Respect sometimes involved presenting alternatives families might not have sought or initially welcomed.

Lesson 2: Families need a facilitator to help them to consider different options. The assistance of someone who a family saw as knowledgeable and trustworthy was pivotal in achieving a family-based alternative to a congregate care facility. Families whose children lived in facilities often saw no realistic alternative. The lack of imaginable alternatives was not simply the result of a lack of information, but rather the lack of someone to help them explore possibilities, and the lack of people to work with them to bring a different vision of the future into reality.

Lesson 3: Systems need to devote energy to system change to enable alternatives. It took a lot to build and sustain a system of services and supports that enabled children living in facilities to move to families. It required the time, energy, focus, and action of many people but it was possible.

Experience showed that moves to family homes became the preferred living arrangement under three conditions:

1. **Families** were offered adequate support.
2. **Facilitators** were available to assist families to consider and implement a different alternative.
3. **System representatives** collaborated to improve services and supports and remove barriers.

Families, facilitators, and system representatives each play a role in making family life possible. Each of these parties must engage in *imagining different* as a prerequisite to *achieving different*.

INCLUDE ME UPDATE



We are implementing PATHS in some of our Include Me schools as a Trauma Informed Care curriculum. Students with disabilities are vulnerable to trauma at school and at home. PATHS stands for Promoting Alternative Thinking Strategies. It teaches students how to express their emotions and regulate their behaviors in a healthy and productive way. For additional information, contact Claire Sonneborn at csonneborn@includemepa.org.



The Arc™

Pennsylvania

The Arc Pennsylvania
301 Chestnut Street
Suite 403, Pennsylvania Place
Harrisburg, PA 17101
717.234.2621
www.thearcpa.org

The Pennsylvania Message is published by The Arc Pennsylvania.

The Arc Pennsylvania is affiliated with The Arc of the U.S. and 33 local chapters serving 57 counties and 8,000 members.

IMAGINE DIFFERENT...ACHIEVE DIFFERENT TOOLKITS

The Imagine Different Coalition invites you to review three workbooks developed to provide detailed advice and ideas to help children move from facilities to families. They were written with national expert guidance informed by over thirty years of experience with moving children from facilities into families.

These imaginative workbooks are written for three audiences:

1. **Family members** looking to learn about different services and supports.
2. **System representatives** who want to re-imagine Pennsylvania's system of family-based alternatives to congregate care facilities.
3. **Facilitators** interested in helping individual children with disabilities currently living in facilities to return home or move into loving families.

You can view or download workbooks at: <http://www.imaginedifferent.org/toolkit>.

The Coalition has also developed additional **information and materials** describing the problems and potential solutions to support family life for children. See www.imaginedifferent.org.

IF YOU'RE INTERESTED IN JOINING THE IMAGINE DIFFERENT COALITION, GO TO www.imaginedifferent.org. For additional information about the Imagine Different Coalition, please contact Katie Lewis, Coalition Organizer, at klewis@pealcenter.org.



MISSION STATEMENT

The Arc Pennsylvania promotes the human rights of people with intellectual and development disabilities and actively supports their full inclusion and participation in the community throughout their lifetimes.